

AMENDED IN ASSEMBLY FEBRUARY 22, 2010

AMENDED IN ASSEMBLY FEBRUARY 16, 2010

CALIFORNIA LEGISLATURE—2009–10 REGULAR SESSION

## **Assembly Concurrent Resolution**

**No. 117**

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### **Introduced by Assembly Members Hill and Huffman**

(Principal coauthors: Senators Corbett and Leno)

(Coauthors: Assembly Members Ammiano, Anderson, Block,  
Caballero, Coto, Fletcher, Fong, Galgiani, Harkey, Hayashi,  
Audra Strickland, Swanson, Torlakson, and Villines)

(Coauthor: Senator Wyland)

February 4, 2010

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Assembly Concurrent Resolution No. 117—Relative to Rare Disease Day.

#### LEGISLATIVE COUNSEL’S DIGEST

ACR 117, as amended, Hill. Rare Disease Day.

This measure would proclaim February 28, 2010, as Rare Disease Day.

Fiscal committee: no.

- 1 WHEREAS, There are nearly 7,000 diseases and conditions  
2 considered rare (each affecting fewer than 200,000 Americans);  
3 and  
4 WHEREAS, While each of these diseases may affect small  
5 numbers of people, rare diseases as a group affect almost 30 million  
6 Americans; and

1 WHEREAS, Many rare diseases are serious and debilitating  
2 conditions that have a significant impact on the lives of those  
3 affected; and

4 WHEREAS, While approximately 360 orphan drugs and  
5 biologics have been approved for the treatment of rare diseases  
6 affecting between 11 and 14 million people according to the United  
7 States Food and Drug Administration, that leaves well over 15  
8 million Americans affected by rare diseases with no treatment  
9 specific to their disease; and

10 WHEREAS, Individuals and families affected by rare diseases  
11 often experience problems such as a sense of isolation, difficulty  
12 in obtaining an accurate and timely diagnosis, few treatment  
13 options, and problems related to accessing or being reimbursed  
14 for treatment; and

15 WHEREAS, Some rare diseases, such as Lou Gehrig's disease  
16 and Huntington's disease, are relatively well known, many others  
17 are not known at all by the public, making patients and their  
18 families bear a large share of the burden for fundraising and  
19 research; and

20 WHEREAS, Because *nearly* one in 10 Americans have a rare  
21 disease, ~~millions of residents of California are among those affected~~  
22 ~~by those diseases; and Californians are among those affected by~~  
23 ~~those diseases; and~~

24 WHEREAS, The National Organization for Rare Disorders  
25 (NORD) is organizing a nationwide observance of Rare Disease  
26 Day on February 28, 2010, on which patients, medical  
27 professionals, researchers, government officials, and companies  
28 developing treatments for rare diseases will join together to focus  
29 attention on rare diseases as a public health issue; now, therefore,  
30 be it

31 *Resolved by the Assembly of the State of California, the Senate*  
32 *thereof concurring,* That the Legislature proclaims February 28,  
33 2010, as Rare Disease Day in California; and be it further

34 *Resolved,* That the Chief Clerk of the Assembly transmit copies  
35 of this resolution to the author for appropriate distribution.